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AUTHOR Moore, Cory
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ABSTRACT

This paper, by a parent of a child with severe mental and physical disabilities, discusses why parent/professional teaming is important to maximize benefits for children and youth with severe disabilities. It recounts the family's experience with the impact of disability. Strategies for effective parent/professional teaming are outlined, stressing the importance of professionals understanding parents as individuals, and the value of empathy, respect, and efforts toward true collaboration. Specific suggestions cover inclusion of parents in team meetings, joint development of Individualized Education Programs, personal communication with parents, avoidance of jargon, use of round (rather than rectangular) tables in meetings, careful planning for meetings, inclusion of the student (and sometimes siblings) in meetings, encouraging parents to bring a relative or friend, use of a comfortable communication style, follow up of meetings with a thank you note, and involvement of parents at all levels of the education system. (Contains 17 references or additional resources.) (DB)

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Maximizing Family Participation in the Team Process

by
Cory Moore
The Parents' Place of Maryland

A parent discusses why parent / professional teaming is important to maximize benefits for children and youth with severe disabilities.[1] *One family's experience with the impact of disability is described. Strategies for effective parent / professional teaming are outlined. The need for collaboration in creating inclusive schools is also discussed.*

I share first with you an "observation about life" from a delightful book called *Lizard Tales* by William R. Davis (1988).

> *Iron and Steel lizards are very good little lizards. As a matter of fact they can be especially dear little lizards -- assuming, that is, they've been properly tempered. In the shadows of a blast furnace two of these lizards were talking. They said, "What I like to hear are experts. A week isn't complete anymore unless I can listen to at least one expert. An expert, after all, is someone who can speak with absolute authority -- and certainly in these unsettled times the world needs experts who can speak with absolute authority.*
>
> *What about yourself, by the way. You've studied, you've traveled, you've written, you've lectured -- can you brighten my week along the lines I've just mentioned? Tell me something you can say with absolute authority."*
>
> *"Very well. No matter what the circumstance I rarely know exactly what I am talking about -- and I can say that with absolute authority."* (Davis, 1988)

I am no expert on communication, and I am no expert on children and youth with severe disabilities, but I am a parent who has dealt with lots of parents and professionals, and I do have thoughts to share. For sixteen years, I worked at the Association for Retarded Citizens (ARC) in Montgomery County, Maryland. I talked with many parents of children with mental

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retardation who were searching for answers. Today, I am the Co-Director of The Parents' Place of Maryland, a Federally-funded parent training and information center that helps families to, among other things, negotiate the world of special education. In this capacity, I again have the opportunity to talk with many parents.

Those students with serious communication problems or with other severe disabilities -- who, under public law, entered schools at kindergarten age -- are now graduating. The regulations governing Public Law (P.L.) 94-142 indicated that the parents of these children would have the right to participate throughout their children's school careers as equal members in the team process. And yet the very same concerns that I listened to from parents in my role at the ARC, I hear now from new parents.

Parents arrive at individualized education program (IEP) meetings anticipating cooperation, only to find, in the middle of the table, brochures explaining how to file for due process. A father who is a lawyer in the Civil Rights Division of the Justice Department told me of his feeling of intimidation when he walked into the room of seated strangers who were there to discuss and assess and make decisions about his young son. If a civil rights lawyer is intimidated, how must the single parent for whom English is a second language feel? Other parents talk about their vision for an integrated school day in the neighborhood school for their daughter with severe disabilities, and teachers and therapists look stunned. The school administrator patronizingly explains why the child's "problems" preclude her from being in a typical setting. There will clearly be no teaming.

Parents are informed in letters that their children are being returned to the community from residential placements, but the parents are not advised that appropriate accommodations will be put in place.

Parents feel judged -- for their child's behavior, for their child's disability. They feel no sense of partnership. The law got us in the room, but it didn't guarantee that our voices would be heard.

Recently, I sat with a mother at a placement meeting regarding the needs of her five year old son. Listening to a brutal evaluation, she tried to brush away the tears as they spilled. Not one school system professional acknowledged her feelings; their judgements concerning the child droned on.

What parents want is to feel that people in school systems care about their children. Instead, they themselves feel disrespected and intimidated. Until parents are truly valued as the experts they are concerning their own children, until they are respected for their contribution as "home information specialists," our schools will continue to foster angry or fearful families.

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I will discuss strategies for involving and empowering parents. What needs to be said upfront is that attitudes can get in the way of collaboration. Parents *and* professionals have valuable perspectives to contribute; those perspectives and the goals and expectations for the child are not always in agreement. This truth should not be seen as a deterrent to setting up the best possible education for the child but, rather, as an opportunity to share ideas, expand horizons, and arrive at consensus.

If professionals are to be effective in communicating with parents, they need to take the time to understand the parents with whom they deal. Each parent of a child with a severe disability brings a history. We carry throughout time the memory of when we first learned that our lives would never be the same. Helen Featherstone (1982), in her remarkable book *A Difference in the Family*, expresses it this way:

> *When I was twenty-five, a friend told me that her brother had been killed in a motorcycle accident two years earlier. She said, "Nothing bad ever happened to me before." I turned this statement over in my mind for a long time. What could she mean? Bad things happen to everyone -- even the luckiest people. Two years later I learned that my newborn son was blind; on that day I remembered her words. Now I understood them. I knew that nothing bad had ever happened to me before.* (p. 4)

Every future encounter with every professional is affected by that first experience. If professionals can understand some of that early impact, they will be able to understand and team with parents.

Allow me to share one parent's perspective. While the stories and the details of other families will be different, the feelings are universal.

I am the mother of two daughters and a son. All three of my children are special, unique individuals. It is my middle child who has been my teacher and guide, the catalyst for my professional life and my personal values. It is because of her that I have found my voice, that I feel passion about issues affecting the conscience and mores of our country. It is because of this daughter that I can address the issue of parent/professional collaboration.

The young woman of whom I speak was mainstreamed into our family 28 years ago. She carries a variety of labels. The one we use is ... Leslie. After a difficult birth and an operation to remove a multicystic kidney when she was less than three days old, Leslie came home. She was a sweet, quiet, placid baby with eyes that crossed but did seem to follow movement. But early, so early, I recognized significant differences. Her head continued to need support; her sister Laurie had held her head up within a few weeks. Leslie moved so little. She didn't do the wonderful, physical, baby things I remembered with my older child. She wasn't hitting the developmental milestones in the books I pored over. My pediatrician assured me that my fears were groundless, that I was

being unfair in comparing Leslie to her precocious older sister.

I found my answer when Leslie was seven months old. I finally persuaded the pediatrician to refer us to a specialist. After a five minute examination of my baby, the neurologist we saw asked us to sit down. It was his judgement, he said, that she would never learn to sit, stand, walk, or talk; never care for herself; and that, if pressed to define her I.Q. -- and I can assure you we were far too numb to be pressing anything -- he would evaluate her at about 15 to 20. He also asked if he could perform a tissue biopsy on her leg muscle for a research experiment that he was doing. At that point I was able to find my voice.

The umbrella label he offered was "brain damage, etiology unknown." One subcategory, back then, was profound mental retardation. This pronouncement was not accurate. A story to illustrate: Leslie was the star recently in a small theater production for adults with disabilities, and she later told me that, following the Saturday afternoon performance, she had to take a nap. "A nap!" I said, responding to her tone. "In the middle of the day?" "Yes," said Leslie. "*I* was not tired. My head was tired." Those of you who have given speeches, held workshops, or taught classes know that she has captured the essence of the experience. To paraphrase a recent book title by an advocate (Kaufman, 1988), Leslie may be retarded but she sure isn't stupid!

A second label was orthopedic handicap. Leslie crawled for the first time when she was six years old. She has no trunk control; years of physical therapy have taught her reciprocal motion, which aids her in doing transfers from her wheelchair, but it will never teach her to walk.

Leslie has a chronic health condition. She is prone to migraines; on 5 occasions in her 28 years, they have been hemiplegic migraines, which paralyze one side of her body and, depending on the side of the brain affected, can cause her to became aphasic as well. Her first massive episode at age 11 sent her to a residential rehabilitation school 326 miles away from us for 15 months. She literally had to learn to talk and use her body again.

Leslie is speech-impaired. It takes people new to her a bit of time to understand her. But it's worth taking the time; she has interesting observations to make. I was at her apartment recently when the phone rang; the call was for Leslie. I watched her response, realizing rather quickly that it had to be a telephone solicitor on the other end. After several minutes, Leslie spoke for the first time since her initial "Hello." "I not want to take it," she said. The person who had called hung up, and Leslie did, too. I asked her, "What was he saying?" "He say, Lip, yap, yap, yap." "You know," I told her, "You don't have to listen all the way through." She gave me a Leslie look. "Mom," she said, "I not want to hurt his feelings!"

Back in the beginning days, there was no humor, no relief. I didn't cope well following the initial diagnostic trauma. For a while, I saw only what the labels conveyed, not the sweet baby I held and nursed and loved. This is a sentiment I've heard from many parents as they

learn to adjust. I felt devastated, depressed, lonely, and isolated. Ken Moses (1987) tells us that "parents grieve for the loss of dreams that are key to the meaning of their existence" (p. 8). Our dream had been shattered.

As each child is unique, so is each history. And we each have our history. But for all families, there are some universal truths.

All parents of children with disabilities go through the same emotions. There is worry, guilt, anger, resentment, helplessness, and often conflict within the family itself about what to do and how to do it. We mourn the child we had imagined, while we deal with the child with whom we live. And at this time of great vulnerability, we question our whole ethical, moral, and religious structure (Roos, 1975). We come suddenly and emphatically to realize a truth that comes to all humans in time: that our lives are often determined by events over which we have no control.

Along our path, we encounter all too frequently those who reject us. To be a parent of a child with severe disabilities is to know prejudice. I will never forget the August day when Leslie was eleven years old and beginning that long, slow recovery from her first massive hemiplegic migraine. She had been a month in the hospital and was at home for six weeks with us before leaving for the residential rehabilitation school that would teach her to talk and move again. Because she was unable to manage the regular swimming pool, we had placed her in the wading pool. There she spotted a toddler sitting across from her. For the first time in over two months, she managed slowly -- so slowly -- to get in a crawling position. I held my breath as I watched her slowly -- so slowly -- begin to crawl toward the little one on the other side. And then, suddenly, there was the click of shoes. A streak of anger that was the toddler's mother ran by, swept her small son into her arms. I can still see the furious look she aimed at her apologetic husband who had allowed this "menace" to confront their baby. That menace was my daughter. The experience left me shaken to the very core of my being. Perhaps, in some ways, it has helped me to understand the value of inclusion, of integrated settings for all children. At the time, it was the most painful rejection and devaluation I had ever felt.

And, yet, this is but part of the experience. Along with the pain, happily, comes joy and amazement and knowledge. A disability confronts us with serious problems. It can also mobilize positive forces we would never have dreamed possible. It can lead to astonishing transformations for some of us. I quote from a book called *The Siege* (Park, 1988), which I found early in my learning. It sustained me in those difficult years. It was re-released with an epilogue from which I quote. Clare Claiborne Park's daughter, Jessy, is the age of my Leslie. Park continues to express truth as I, too, know it:

> *Growth is endless and our lives change and change us beyond anticipation. I do not forget the pain - it aches in a particular way when I look at Jessy's friends [her*

paid companions], some of them just her age, and allow myself for a moment to think of all she cannot be. But we cannot sift experience and take only the part that does not hurt us. Let me say simply and straight out that simple knowledge the whole world knows. I breathe like everyone else my century's thin, faithless air, and I do not want to be sentimental. But the blackest sentimentality of all is that ... which will not recognize the good it has been given to understand because it is too simple. So, then: This experience we did not choose, which we would have given anything to avoid, has made us different, has made us better. Through it we have learned the lesson that no one studies willingly, the hard, slow lesson of Sophocles and Shakespeare -- that one grows by suffering. And that too is Jessy's gift. I write now what fifteen years past I would still not have thought possible to write; that if today I were given the choice, to accept the experience, with everything that it entails, or to refuse the bitter largesse, I would have to stretch out my hands -- because out of it has come, for all of us, an unimagined life. And I will not change the last word of the story. It is still love. (Park, 1988, p. 320)

Before Leslie was three years old, we had dealt with an obstetrician, a pediatrician, a pediatric surgeon, an ophthalmologist, an audiologist, two neurologists, a child development specialist, a physiatrist, and a geneticist. In the next few years were added a dentist, a periodontist, an orthodontist, nurses, intensive care personnel, physical therapists, occupational therapists, music therapists, speech pathologists, and teachers. Few of these encounters were of our choosing. We were sometimes patronized, more than once ignored, frequently pitied. On occasion, we were respected and listened to; we remember those occasions with pleasure.

My solution to maximizing family participation in the team process is common sense. It does not require magic or new and esoteric approaches. Some school systems have developed written strategies for collaborating with parents of children in regular education; I refer you to one compilation of strategies for parent involvement available from the Office of Community Education, Massachusetts Department of Education (n.d.). Their list is equally applicable to parents of children with disabilities. To maximize family participation in the team process asks only for professionals to listen, to understand, and to respect us.

If professionals in the schools can understand where we parents come from, what experiences have shaped our expectations of them, then new kinds of relationships can happen. We need to be seen as individuals, rather than stereotypes. We are not necessarily "the overprotective mother" or "the rejecting father," any more than you are "the insensitive teacher" or "the uncaring administrator." We parents come in different packages, in all shapes and sizes; we span

the continuum. We need to be known, as do our children, in our totality, people with strengths as well as needs. Trust and accept us. Do not ignore or tolerate or humor or dismiss us. When you stop judgement, we *will* be open to you.

We don't need your professionalism; that causes an unbridgeable gulf. We need empathy, Karl Roger's "unconditional positive regard," we need respect, we need to have our contribution valued. We need to participate, not merely be involved. It is, after all, the *parent* who knew the child first and who knows the child best. We parents dream the dream for our children's future. Our relationship with our sons and daughters is personal and spans a lifetime.

I am suggesting that, to create true collaboration, the professional has the major responsibility to change his or her attitude when problems occur. It is the professional who must acknowledge and validate families, who needs to accept parent feelings of distress and even anger.

The following questions are for administrators, teachers, therapists. Do you listen? Or do you participate in what I used to call "The Mother Says" syndrome? Leslie's earliest medical files are filled with negative reports of all the things she couldn't do, the deficits. They would conclude with a paragraph that began with the words "The mother says" and outlined what I reported I was seeing at home. The tone was skeptical and dismissive. I soon stopped sharing.

Do you label all parents as uncooperative or uninvolved because of the few who are? To add perspective, not all parents of typical children are required or expected to be totally involved.

Do you look at the important roles cultures and religion play in how families learn to cope? Attitudes and customs in a child's home may be radically different from your experience; true teaming involves understanding.

Do you help to promote hope, to sponsor the vision of participation in an inclusive setting, life in the community, no matter how severe the disability? We need to hope; without it, we are paralyzed.

How are parents included in team meetings? Do they have a voice? Are they looked to as experts on their own children? Are they asked to share their thoughts and wishes, to describe what would contribute to the family's well-being, as well as to the child's learning? I remember the description of the teenager whose only spontaneous movement was in one hand. For years, physical therapy had been used to try to loosen his tight muscles. A new approach caused something of real significance to happen. In thinking through how this movement could be used in the life-space of this young man, the team of parents, therapists, and teacher decided on a new goal, one in which he would learn to open the lid of a peanut butter jar. As a result of therapy designed to accommodate family interests, this young man could come home from school and open the peanut butter on which he and his younger siblings snacked. It made him proud, it gave him a real place in the daily routine of his family. It was a team decision that made sense.

Is the IEP truly a team effort? Computerized IEPs don't feel individualized to parents. Even if the word "DRAFT" is stamped across the top, parents feel decisions are already in place. Do you share the IEP in advance of the team meeting? Do parents know they can add to a draft, subtract from it, throw it away, or bring in their own?

Do you communicate with parents only through form letters? Or when something goes wrong? Parents of children who can't communicate themselves really appreciate the daily notebook, the phone-in hour.

Do you write and talk to parents in clear, understandable language? Jargon is the shortcut you can use with fellow professionals; for parents, it's an obstacle to understanding. Plain English can be a very good strategy for real teaming. Do you share with parents copies of all reports about their child? Do you try to keep those reports jargon-free?

Do you help parents understand why they're asked to do particular activities at home to further communication skills?

Do you suggest or do you decree? What should a mother say when a speech pathologist talks about the latest augmentative communication device? The mother may know unequivocally that it will be rejected by her child, but how does one share this with an expert without appearing uncooperative? We collected lots of dust-catching equipment recommended by therapists in Leslie's early years; it takes time for a parent to feel empowered enough to question, to challenge.

Do you remember that a team is a group of players all playing on the same side? Just as individual members of a baseball team have different contributions to make, so do the individual members of the team that is designing the IEP for each child. As the professional, you bring your valuable expertise. The parent brings his or her own unique and equally important perspective.

Do you take the time to prepare for meetings? I remember a placement meeting when the chairman referred to "your son, Leslie." Fortunately, I have a sense of humor!

Where do you hold meetings? There will be some parents who would appreciate meetings in their homes. There will be others who feel fright at coming into the school building. Would it be possible in those cases to meet on neutral ground: a community center, a library? One principal in my home town holds a potluck dinner for parents a week before school opens. He gets a willing parent to help organize it, and it takes place in a meeting room in a huge apartment complex where many of the children live. He shares proudly that all the parents of the children in his school who receive special education services come to team meetings.

What is the room like where you meet with parents? Must there be the dreaded rectangular table? A round table would contribute so much more to a sense of partnership.

Do parents know why the meeting is happening, who will be there, and what to expect? If they arrive early, is there a comfortable place to wait?

Is everyone seated around a table when parents are ushered in? It is overwhelming to walk into a room of

seated professionals, all looking at you, the last arrivals. At the least, if the school team members are standing, parents won't feel on exhibit or like outsiders.

Do you take the time to identify everyone in the room by name and area of expertise? Perhaps each professional could say a few words about the way in which they know the child. Extra minutes at the beginning of a meeting may forestall many angry minutes after the meeting.

What is your communication style? Do you speak in a warm tone, do you smile, show concern? Does your body language indicate openness and interest? What image do you project? A special education teacher in my school system is referred to by parents as "Miss Perfect." They don't feel comfortable when they talk with her. One of *my* very best happenings was the time early in my career when I was going to speak to a group. I had taken special pains to look competent and confident. My hair was in order, my makeup was just right, my dress was new and professional. When I got out of my car in the parking area to go into the meeting, I suddenly realized that I was wearing my fuzzy pink slippers. It was a humbling experience and one I came, later, to appreciate. I learned that day not to take myself so seriously.

Do you include the student in meetings? Students with even the most severe disabilities have ways of telling us important things. A child's behavior or gesture may indicate that the choice being discussed is the wrong choice. All people are entitled to have some control over decisions directly affecting them.

Are the student's brothers and sisters invited? They often have valuable ideas and observations to share. The student's same age peers -- neighbors, classmates, friends -- may have new strategies to propose.

Do you suggest that parents bring along a relative or friend? It is very helpful to parents to have someone with whom they can process the content of a meeting when the meeting is over. If that suggestion were to come from the school, it would truly imply cooperation and understanding of how difficult meetings can be for parents.

Do you really understand and believe that parents are valuable team members? It is important to remember that decisions made in each meeting can have a long-term effect on the life of an individual. A goal in Leslie's IEP for several years running was to tie her shoes. She worked hard to meet the goal, both at school and at home. And one wonderful day an excited voice summoned me. "I did it, Mom! I did it!" And she had. Her shoes were tied; loosely, but tied. We all reinforced her with praise and excitement. The next morning, I put her shoes next to the pile of clothes she had helped to select and turned to the door to allow Leslie the necessary time to dress herself. An incredulous voice stopped me. "You mean," she said, "you mean I have to tie them forever?" Think of all the time that was wasted on the goal of shoe-tying. Velcro works just fine!

In discussing goals, do you talk about quality of life, satisfaction, choice, self-determination, empowerment? Do you look to the student's future? Where

he or she will live, work, learn, communicate, and play when school days end? These are important issues to focus on, even in the earliest years.

How do you express yourself? It is devastating for a parent to hear a speech pathologist refer to "serious speech delay," even though that parent understands that this is the case. How much more helpful to hear, "We need to work together to assist him in communicating."

Do you follow up meetings with a thank you note? Little things can make parents eager to work with you.

Do you start from the premise that every parent is doing the best he or she can? One mother told me recently, "I chose to be a parent. I didn't ask to be an advocate." Allow parents their own decisions about how and how much they want to be involved.

Look carefully at your attitudes. Are you judgmental? I know my child. I know her medical history and her vulnerability. I should not be called overprotective and possessive. I know my child's limitations. I should not be classified as negative when I acknowledge them. I know my child's gifts and strengths. Don't put me down as unrealistic or unaccepting when I list them.

Do you know the appropriate resources in your state and community which can help you be as effective as possible in involving parents? Local parent advocacy groups can be of significant help to you in your communities. All the states now have parent training and information centers; they can be valuable allies in your learning the best ways to collaborate. State Department of Education conferences, summer institutes, local inservice programs, and other training opportunities might utilize training teams that incorporate a parent, administrator, and educator to share views and perspectives.

Are parents invited to serve on teacher-hiring and planning committees, on parent-teacher task forces, as classroom volunteers? Do all parents feel welcome in your schools?

There are many problems in the educational system of today. Attention is being paid to what has gone wrong. This is the best of times to invest energy in new ways, in new thinking. Rather than continue with what hasn't worked, it's time to start again ... with new values, new expectations, and a new commitment. If educational systems are to be redesigned to produce the best possible citizens of tomorrow, teaming of parents, teachers, administrators, and state departments of education is essential. It will take more than adding on science and math courses. I firmly believe that part of what it will take is including all children in the neighborhood in the life of every school. This will take adjustment and adaptation and technology. It will take enlightened attitudes and principals who are excited by, rather than fearful of, challenge. It will take convincing parents of children with disabilities and parents of typical children that the restructured school is not a "dumping ground" but, rather, a community that can individualize instruction for each of its students. It will take training all teachers about all students. It will take modeling appropriate attitudes for typical students to see. It will take special

educators understanding that "special" education is no longer special enough. It is time to move on.

The supports that students with severe disabilities need are not separate facilities and a curriculum based on a developmental model but, rather, circles of friends, opportunities to cultivate self-esteem, and learning the skills necessary for meaningful adult lives in their communities. More and more of today's parents are looking to the neighborhood schools to open their doors. This will require a new kind of teaming that will involve all teachers, all parents, and all students. It is an exciting challenge.

I will end by first sharing with you the summary of an ongoing parent contact at our parent training and information center and then by offering a professional observation. A young man with autism who had been asked to leave two private day programs and who was then assigned to a segregated public school for students with severe to profound retardation is now using facilitated communication. His IQ is currently measured at 116, but since he felt "insulted" by the first day's tests and refused to answer the beginning block of questions, it is doubtless higher. It was his mother who opened his door to the outside world by attending a conference and trying facilitated communication at home. This young man's mother has accomplished what I would hope we could count on from professionals. Never underestimate the drive or the ability of parents as they explore possibilities for their sons and daughters!

Finally, I offer this quotation from a Community Crisis Team psychiatrist in Dane County, Wisconsin: "No family is impossible to work with. If that's your experience, you're not understanding their needs. They'll bend over backwards for you if you do understand."

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